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EHDN *News*

EUROPEAN **HUNTINGTON'S DISEASE** NETWORK

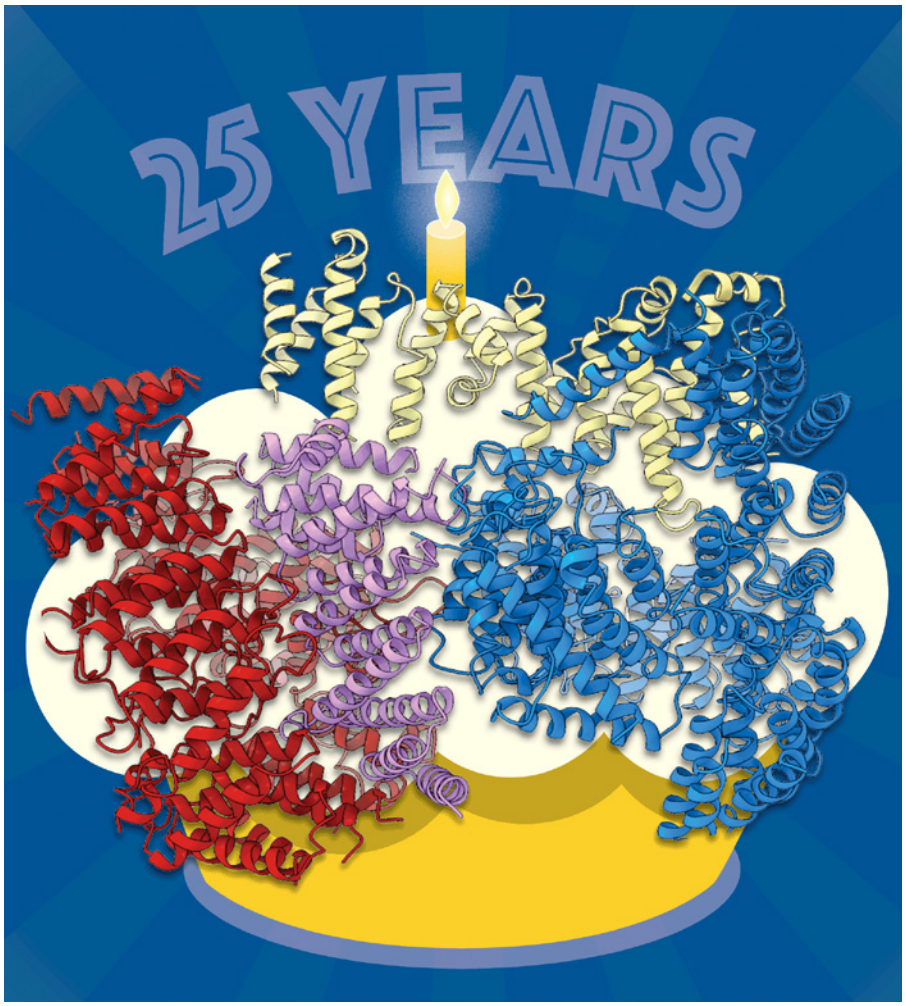

Illustration: Gabriele Stautner, Artifox.com

The structure of the huntingtin protein as elucidated by the teams of Ruben Fernandez-Busnadiego and Wolfgang Baumeister (Max Planck Institute of Biochemistry, Munich) and Stefan Kochanek (Ulm University) in Germany, who will present the research at the EHDN plenary meeting in Vienna in September. The publication of this structure coincides with the 25th anniversary of the identification of the huntingtin gene.

INTERESTED IN PARTICIPATING IN CLINICAL TRIALS? APPLY ASAP FOR HD CLINICAL TRIAL SITE CERTIFICATION!

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Thinking out of the tank

Michael Orth, Central Coordination

The EHDN Science Think Tank continues its work of reorganisation, rationalisation and innovation with the aim of keeping the network at the cutting-edge of HD research, and well-adapted to support complementary research efforts.

It's worth remembering that the research EHDN promotes isn't just directed at finding new and better treatments.

Imprint:
Editorial Board of EHDN News:
Laura Spinney, Editor (Paris, France)
Gabriele Stautner Artifox Communication Design (Ulm, Germany).

It is equally important that we develop valid outcome measures, or phenotypes, and validated assessment tools, since all three will be needed to improve quality of life for those who carry the HD mutation.

The EHDN working groups (WGs) continue to pursue their important scientific enquiries, and where necessary to refine their goals. To date, five WGs have issued mission statements that are available on the EHDN website. They are the Behavioural Phenotype, Cognitive Phenotype, Genetic Modifiers, Physiotherapy and Young Adults WGs.

Along with the new task forces, the WGs aim to lay the groundwork for the identification of new treatments and the improvement of existing ones. The Genetic Modifiers WG is working to identify genetic variants that influence HD phenotypes independent of the HD mutation, the first step towards the development of treatments designed to exploit these effects. The Physiotherapy WG provides guidance for the use of physiotherapy in clinical practice and how best to promote an active lifestyle. The Behavioural Phenotype and Cognitive Phenotype WGs, along with the driving and dysphagia task forces, work on the definitions of clinical phenotypes and tools for assessing those phenotypes for use in research as well as in the clinic. A future goal of HD research is to offer treatments to people carrying the HD mutation before they develop the disease. To this end, it is vital to encourage young adults to feel a part of the community and to participate in research, which is the aim of the Young Adults WG.

The think tank is developing new initiatives all the time, and we encourage you to follow its progress in this newsletter. To recap, it brings together EHDN staff who are closely involved in supporting scientific research—including members of the Executive Committee, the WGs and Central Coordination—and it engages with the HD research community in three ways:

- Researchers may contact the think tank for help in identifying potential collaborators or funding opportunities, or to discuss scientific ideas
- The think tank welcomes suggestions of research topics, and has provided a contact form on its website via which these can be submitted
- The think tank may occasionally propose specific research topics that could be addressed by a dedicated task force working for a defined period of time.

For more information about the HD Science Think Tank, please contact Leonor Correia Guedes: leonor@euro-hd.net

Obituary: Daniel Zielonka pays tribute to Włodzimierz Krzyżosiak

Włodzimierz Krzyżosiak, EHDN member and leading HD researcher, passed away suddenly in December 2017. Born in 1949, in Rawicz, Poland, he completed his chemistry studies in Opole before taking up a post at the University of Poznań. In 1975 he joined the Institute of Bio-organic Chemistry of the Polish Academy of Sciences, where he became the head of the Department of Molecular Biomedicine. He published 120 scientific papers and promoted 19 PhD students. His most important achievement in the HD field was described in a paper published in *Molecular Cell* in 2007, in which he described a dicer role in gene silencing. This initiated a line of research that culminated in the gene silencing therapies whose early, promising results in humans are described elsewhere in this newsletter. European science is poorer for the loss of this talented scientist who was also known for his kindness and encouragement of others.

Update: Clinical trials

Jenny Townhill and Tim McLean, Central Coordination

Since the last edition of this newsletter there have been some exciting developments in HD clinical research, including promising results and progress in gene therapy trials. The following trials have been endorsed by EHDN.

IONIS-HTT$_{Rx}$ (completed): Positive results in this six-month, phase 1/2a study of a novel antisense oligonucleotide (ASO) were announced by Ionis Pharmaceuticals in December 2017. This was the first therapy to enter clinical development that is designed to address the genetic cause of HD directly (a detailed description of how the drug works can be found here). The trial involved 46 patients with early stage HD in the UK, Germany and Canada. Dose-dependent reductions of mutant huntingtin were observed in those treated with the drug, which was shown to have an acceptable safety and tolerability profile. The results are due to be presented by Ionis and Roche Pharma at conferences in the first half of 2018, and submitted for publication. An open-label extension study for patients is ongoing. Roche has exercised licensing rights to develop the drug, and is expected to launch a major trial to test its clinical effectiveness. EHDN Central Coordination has issued a statement about the findings to date.

Open Pride (completed): This Teva Pharmaceuticals-sponsored open-label study was open to all participants who had completed 12 months in the phase 2 pridopidine study Pride-HD. Although Pride-HD did not meet its primary endpoint, the open-label study was initiated on the strength of trends in the data that suggested some functional improvement. The planned treatment period of 52 weeks was later extended to 104 weeks or more depending on regional approvals. At the end of October 2017, though no safety concerns had been reported, Teva announced the study's immediate closure and the last patient completed treatment in January 2018. Teva has since confirmed its commitment to an expanded access/compassionate use provision at least until the end of 2018. This is expected to be operational by the second quarter of 2018.

PRECISION HD1 AND HD2: These two phase 1b/2a trials, which are sponsored by WAVE Life Sciences and which follow the same protocol, use ASOs to target distinct single nucleotide polymorphisms in the huntingtin gene (SNP1 and SNP2). The ASOs target the expanded huntingtin allele only, allowing normal huntingtin to continue to be expressed (a detailed overview of the trials can be found here). They were initiated in July 2017, and eligible participants are being pre-screened for SNP1 or SNP2 before those who qualify are enrolled into the appropriate study. Around two-thirds of HD patients are currently estimated to carry SNP1, SNP2 or both. WAVE plans to enroll a total of around 50 early manifest, stage 1 and stage 2 HD participants to each study, through sites in Canada, Europe and eventually the US.

LEGATO-HD: Teva remains committed to the successful completion of this 12-month, phase 2 safety and efficacy trial of laquinimod, which the last patient is expected to complete in June 2018. Efforts are currently focused on ensuring that participants who have yet to complete the trial attend all required study visits, and on data-cleaning. If you are a site participating in the study and need advice on how to boost participant engagement, please contact Jenny Townhill (details below).

HD-DBS: This investigator-initiated trial of pallidal deep brain stimulation for HD is approaching its recruitment target of 50 participants. To date, 21 participants have been randomised and others are due to be screened in the next few months. A French site, Amiens-Lille, is awaiting regulatory approval and should be activated early in 2018. Eligible participants are those with moderate stage HD, with uncontrolled choreic symptoms for which current pharmacotherapy is proving unsuccessful, and who are able to give independent consent. Physicians in participating countries (Germany, Austria, Switzerland and soon France) are encouraged to refer eligible participants to the trial sites.

PACE-HD (Physical Activity and Exercise Outcomes in Huntington's Disease): This recently endorsed activity intervention study, which is led by Cardiff University in the UK and funded by the Jacques and Gloria Gossweiler Foundation, has two components. The first is a one-year prospective evaluation of physical activity and physical fitness in individuals with HD, to be conducted alongside annual Enroll-HD assessments. The second is a within-cohort randomised control trial (RCT) of a one-year exercise intervention in HD, that will compare a supported and structured aerobic exercise training programme to usual activity. The study plans to enroll 60 early-to-mid stage HD participants into the prospective cohort and 60 participants into the RCT cohort, at six sites in Germany, Spain and the US. Recruitment is expected to get underway in the first half of 2018.

For more information about, or to provide feedback on, EHDN-endorsed studies, please contact Jenny Townhill: jenny@euro-hd.net

Sites interested in participating in upcoming clinical trials should apply as soon as possible for HD Clinical Trial Site Certification. Certification under this scheme will increase their visibility and improve their chances of being assessed further for specific feasibility.

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CHDI Therapeutics 2018

The 13th Annual HD Therapeutics Conference, organised by CHDI in Palm Springs, California, has just concluded. Anyone who is interested in the proceedings, but wasn't able to attend, can still browse the live commentary provided by the HDBuzz team from the meeting.

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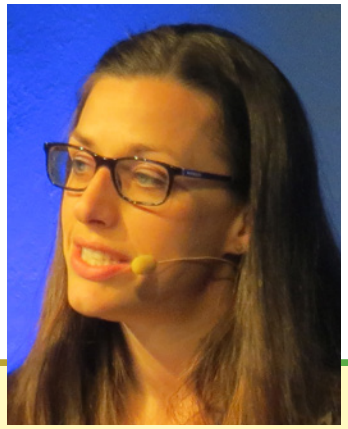
Update: Enroll-HD

Olivia Handley, Global Platform Manager, Enroll-HD

Since it was launched five years ago, the Enroll-HD study has grown exponentially. More than 150 sites are now submitting data and samples for a cohort of 16,000 participants. Three data sets have been released, the most recent of which contained data from 8,714 participants. There have been 165 approved applications for data use and 14 biosamples distributions, three of which were for non-renewable biosamples. A fourth data set covering more than 10,000 participants is scheduled for later this year.

Enroll-HD serves as a platform supporting clinical research projects and trials. It is currently providing resources and guidance for three neuroimaging studies (iMark, iRest, iMagemHTT), two biospecimen collection studies (the cerebrospinal fluid collection study HDClarity, and the semen collection study Origin-HD), an imaging/biospecimens study in young gene expansion carriers (HD-YAS), an exercise-intervention feasibility trial (PACE-HD), and a health economics study (HD-Charge). The type and level of support depends on the study requirements with respect to monitoring, database development and management, and rater training. Enroll-HD is also providing input to study-level and participant-level feasibility assessments for several upcoming clinical trials.

In 2017 the focus has been on planning for the next five years and beyond. On current projections, Enroll-HD is expected to have recruited 20,000 participants by 2020. This prospect has led the study leadership to take two steps. The first is to put the recruitment of new sites on hold (this will not affect the 60 sites already in transition from Registry or new sites that have entered start-up), and the second is to critically review study data with a view to establishing the optimal cohort size and data volume needed for Enroll-HD to achieve its objectives.



Enroll-HD Objectives

- To enhance the design and **expedite the conduct of clinical trials**
- To improve our **understanding of the phenotypic spectrum (clinical signs and symptoms)** and disease mechanisms of HD in humans
- To **foster good clinical care** and improve health outcomes

A "steady-state" statistical model has been developed to help identify the optimal cohort size needed to support the development of therapeutic interventions that are mainly targeted at early manifest HD populations. This model—which can also be used to inform and assess recruitment strategies—has highlighted a need to prioritise the recruitment of premanifest and early manifest participants, since these are the participants most likely to be recruited to future trials.

Significant resources are required to maintain Enroll-HD in its current form, and as participants progress to later stages of the disease (stages 3 to 5 currently represent 15-20% of the cohort), maintaining annual visits will become more challenging for participants, families and sites alike. Morever, several tasks in the assessment battery lose sensitivity at later stages of the disease. For these reasons, with support from the Enroll-HD Steering Committee, CHDI is planning a new study protocol, Enroll-HD Lite. This will introduce a leaner assessment battery specifically designed for participants in later stages of HD, who will transition from the current Enroll-HD study. An Enroll-HD Lite protocol advisory committee is working towards finalising the protocol by May 2018, and the new study will be formally announced at the Enroll-HD Congress in the same month. The first sites are expected to enter the study by the end of 2018.

Enroll-HD Congress

The Enroll-HD Congress will take place in Quebec City, Canada, from 20 to 22 May 2018.

Fairmount Le Château Frontenac, Quebec City, venue for the 2018 Enroll-HD Congress

This global clinical conference and site investigator meeting will address modifications to the Enroll-HD platform and observational study, highlight advances in HD clinical research, disseminate new scientific findings, promote collaboration and data-sharing, and provide an opportunity for the Enroll-HD clinical community to network and share experiences. Delegates will include site investigators and study coordinators, as well as colleagues from academia, industry and the wider HD community.

CHDI is inviting submission of poster abstracts that describe either research that uses Enroll-HD clinical data, or activities related to Enroll-HD such as study co-participation, innovative site operations and recruitment strategies. An independent scientific review panel comprising members of the Enroll-HD Scientific Publication Review Committee will review these submissions and select posters to be presented at the conference.

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Nikhil Ratna in Kerala, India, 2017

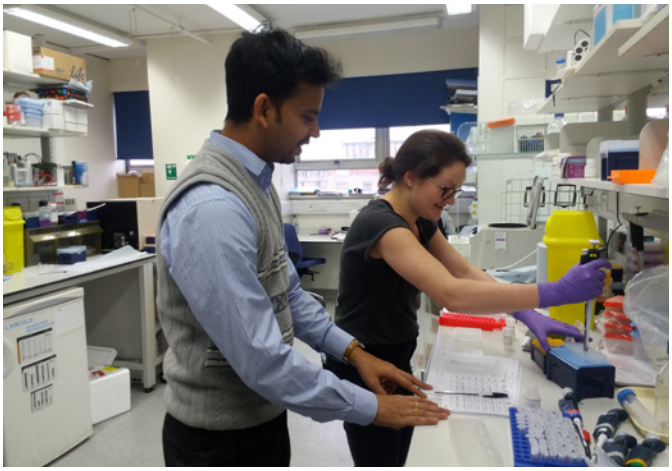
Fellowship exchange programme: from Bangalore to London (and back)

Nikhil Ratna

The six weeks I spent at University College London's HD Centre in late 2017, thanks to the fellowship exchange programme (FEP) sponsored by EHDN and the European section of the International Parkinson and Movement Disorder Society (MDS), allowed me to satisfy my abiding curiosity as to how HD clinics and research work outside India.

I am a medical graduate pursuing an integrated clinical doctoral fellowship programme at the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore. My clinical work involves the management of HD and similar disorders, as part of a team specialising in movement disorders, while my thesis is focused on deep clinical profiling of Indian HD patients and HD molecular pathology.

Nikhil and Nancy Wexler



Nikhil and Lauren Byrne at work in UCL's biomarker lab

India has very few genetic testing centres, and those it has often lack genetic counsellors or any affiliation with a hospital. India also has very few clinicians specialising in HD. The disease is under-studied in terms of epidemiology and basic and clinical research, and this affects the way it is diagnosed and managed. Even at NIMHANS, the country's leading neurology institute, HD falls under the broader specialisation of movement disorders, and movement disorders are represented at only a few centres nationwide, most of which are to be found in large cities.

When I first encountered HD patients two years ago, I was struck by the absence of a multidisciplinary approach to their management. Following diagnosis on the basis of a genetic test, they were generally offered pharmacotherapy, and follow-up was poor or lacking entirely. This was partly due to the stigma attached to an incurable genetic disease, even though treatments are available that improve patients' quality of life, and their participation in research could bring great benefits.

With the encouragement of psychiatrist and molecular geneticist Sanjeev Jain, who is passionate about treating HD, I tried to initiate contact between specialties including physiotherapy, speech and swallowing therapy, psychiatric social work, neuropsychology and Ayurveda. After they lent their support to a multidisciplinary programme, things improved with respect to both diagnosis and follow-up frequency. Sixty new HD cases were diagnosed in two years, thanks to word-of-mouth referrals.

The most obvious difference I see between India and the UK, with respect to HD, is the impact of culture and socioeconomic status. Consanguinous marriage raises the probability of the disease mutation being passed on, in India, while high levels of illiteracy make it difficult to educate Indians about inherited disease. It is not uncommon for patients who can barely afford a square meal to be prescribed costly medicines—another reason follow-up rates are so low—while the stigma attached to a movement disorder that can be confused with drunkenness is greater in a society that is less tolerant of alcohol per se.

At UCL's HD Centre, I observed specialised, multidisciplinary clinics and a highly interdisciplinary (patient- and animal model-centric) approach to research. GPs could refer patients to various disciplines in a coordinated manner. Follow-up rates were high and so were rates of participation in research, about which patients were well-informed. For me, the best aspect of the HD clinics in London was the multidisciplinary discussions that took place afterwards. It was during those discussions that I learned the utility of classifying patients by disease stage, and acquired new protocols for clinical assessment.

Throughout my visit, I had excellent and continuous feedback from my host Sarah Tabrizi, as well as from Ed Wild, Gill Bates and many others. I learned about the observational study Enroll-HD, which I hope will one day be rolled out in Indian centres. With Ed Wild's encouragement, I got involved in translating the wonderful information resource HDBuzz into Indian languages, and I took away plenty of ideas and hope for future collaboration with the UCL team in patient-centric research.

Finally, I was able to make contact with Astri Arnesen, President of the European Huntington Association (EHA), who expressed her willingness to support the Indian HD

community, and I hope to mediate future communication between the EHA and a nascent Indian HD caregiver support group. With the contacts I made in London, and all that I learned there, I aim to help drive important structural changes to the system of care for HD patients in India.

Sarah Tabrizi writes: "We were delighted to host Nikhil at [our HD] Centre. He was an enthusiastic and engaged visitor whom we think learned a lot about both research and clinical care during his visit… It is important to highlight that the exchange was certainly two-way; the Centre team learned about new challenges to realising our shared vision of a world free from HD, and on several occasions his contributions to our team research meetings gave us new perspectives and new ideas."

Fionnuala Margreiter, EHDN's Grants and Collaborations Manager writes: "The 2017 FEP was judged a success by most fellows and host organisations, and as a prelude to their future or ongoing collaborations with EHDN, we look forward to meeting them, along with previous fellows, at the 2018 EHDN plenary in Vienna in September. This year, as part of an effort to refine the FEP so that both parties get the most out of it, we plan to circulate a brief outline of its goals to potential host organisations, so that they know exactly what is required of them and what type of experience fellows should take away with them. We will also ask for a small amount of feedback from hosts once the fellowship has been completed, in addition to the report we ask of the fellow him- or herself, to help us improve the programme still further."

The 2018 round of the EHDN-MDS Fellowship Exchange Programme is now accepting applications.
The deadline is Friday 27 April 2018
and any queries should be addressed to:
fep@euro-hd.net

Fionnuala Margreiter and Bea de Schepper (EHA) at EAN Congress2017

Two grant deadlines…

- **Joint Programme—Neurodegenerative Disease Research (JPND):** joint translational call to support health and social care research and innovation
  Deadline for pre-proposals 6 March 2018

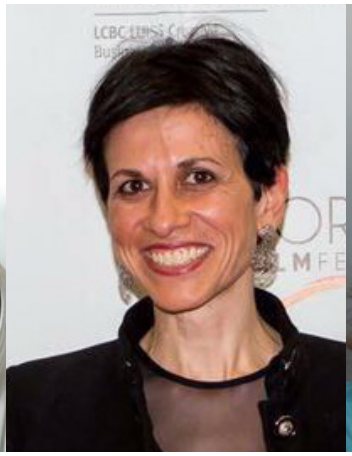
- **Horizon 2020—Rare Disease European Joint Programme Cofund**
  EHDN is preparing an application for this with the European Reference Network for rare neurological diseases.
  Deadline 18 April 2018

…and a funding opportunity for young scientists

There's still (just) time to apply for the **Huntington's Disease Society of America Berman/Topper HD Career Development Fellowship**, a three-year grant to provide support for young scientists to work collaboratively with their mentors and other committed HD health professionals to develop the fellow into an independent HD leader. The awards, of up to US$80,000 a year, are open to young scientists and clinicians from around the world, who are interested in a career in HD research or care.
The deadline is 9 March 2018.
More information and an application form can be found here.

Follow our Grants and Collaborations Manager, Fionnuala Margreiter, on Twitter **@EHDN_GRANTM** for the latest news on EU funding and events and policy developments in the domain of rare diseases.


Berry Kremer


Alba di Pardo


Rosanna Parlato


Rhona MacLeod

Four new seed grants awarded

The first of four projects to have received seed funding recently relates to handling a car, and is associated with EHDN's driving task force. Driving brings mobility and independence, but there comes a time when it is no longer possible for HD mutation carriers. When is that time? **Berry Kremer** of the University of Groningen in the Netherlands, and colleagues, will try to answer that question by performing specialised psychological tests of HD carriers, assessing their performance in a driving simulator and on the road, and questioning their partners and acquaintances. The psychological tests not only measure cognitive abilities such as reaction speed and attention, but also self-reflection and risk-taking. The Dutch group's goal is to define measures that, going forward, will form the basis of personalised advice on fitness-to-drive for individuals with HD.

The second project to have received seed funding focuses on sphingolipids, major components of brain cell membranes, since there is evidence that aberrant sphingolipid metabolism plays a prominent role in the pathogenesis of HD. **Alba di Pardo** of IRCCS Neuromed in Pozzilli, Italy, and colleagues, plan to gather evidence that modulating that metabolic process could be beneficial in HD, and eventually provide a concrete target for novel and effective therapies.

Rosanna Parlato of Ulm University in Germany, and colleagues, will test a hypothesis that the particular vulnerability of striatal medium spiny neurons (MSNs) in HD is related to pathology of those cells' primary cilia. The primary cilia are non-motile, microtubule-based organelles that act as a cellular antenna and provide a reservoir for mutant huntingtin (mHTT), with increased mHTT resulting in increased ciliogenesis. The researchers will monitor neuron- and stage-specific changes in the structure of these cilia in HD mouse models. Concomitantly, they will analyse the neuropathological effects of their absence in MSNs in HD mice. The findings could highlight previously unknown causes of MSN degeneration and, potentially, lead to therapies that modify HD progression.

The fourth and final project to have received funding is a pilot study of the efficacy of a group narrative session in supporting individuals who have undergone predictive testing for HD, and is led by **Rhona MacLeod** of the Manchester Centre for Genomic Medicine in the UK. The aims of the two-hour session are to foster resilience and strengthen existing coping mechanisms. Three genetic counselling narrative groups will be organised, each having eight participants. Those who agree to take part will be asked to complete two short questionnaires, one before and one after the session. They will also be invited to participate in a semi-structured telephone interview two weeks later, the goal of which is to explore their individual experience of the group session.

Seed funds are intended to support pilot studies that will eventually kickstart larger projects.
The next deadline is 1 November 2018.
More information about the programme and how to apply can be found here.

Photos kindly provided by Ed Wild

Tapping into the zeitgeist:

Interview with Ed Wild

In December 2017, the HD community received the news it had been waiting for, a positive result in the first ever clinical trial of a huntingtin-lowering drug. The drug in question, Ionis Pharmaceuticals' HTT_{Rx}, was shown to be safe and well tolerated. Neurologist Ed Wild, a member of the team at University College London that ran the trial, talks to us about the moment the news went public, the work that made it possible, and what happens next.

Why is the outcome of the Ionis trial such big news?

A number of things could have gone wrong. The drug could have been dangerous, for example, or we could have lowered huntingtin in the brain but not been able to detect it in the cerebrospinal fluid (CSF). In the end, the drug was safe, we lowered huntingtin in a dose-dependent fashion, and we were able to detect that lowering. It was like opening your present on Christmas Day and finding the super deluxe version of the thing you had asked for!

What was the most important result for you?

The lowering was dose-dependent, which means that we have control over it. For a patient far from disease onset, for example, we might only want to lower huntingtin by a small percentage. We can now be confident that we can achieve the percentage we want by altering the dose of the drug. Whatever happens next, in the testing of this drug, that is a major step forward.

A number of different strands of research came together to make the trial a success, didn't they?

Yes. The Ionis trial itself was in the works for a decade. In parallel with that, I and others were looking for biomarkers, because we knew that we would need good ones for measuring the clinical effects of potential treatments. In 2015, six months before the Ionis trial got underway, we finally succeeded in measuring mutant huntingtin in CSF, with an assay that we were able to incorporate into the trial. On top of that, last June, we reported what looks like the first reliable blood biomarker of HD, neurofilament light protein (NfL).

Photo: Gabriele Stautner, Artifox.com for EHDN

How do you see these discoveries being exploited in the clinic?

The efficacy of HTT_{Rx} will be tested in the next trial, to be run by Roche, so we haven't proven that it works yet. But if and when we do have an effective drug, one possible roadmap for the clinical management of HD might begin with regular blood tests to measure NfL, before symptoms begin. When it becomes clear that NfL is increasing in blood, we'll switch to the more informative CSF biomarker, and we'll use that to help guide the decision to give a huntingtin-lowering treatment at the earliest time that it's likely to be effective.

There was a huge media response to December's announcement. Did it take you by surprise, given that HD is a rare disease?

Yes and no. Although HD is rare, it's also blazing a trail. Colleagues working on other neurodegenerative diseases are gearing up to run their own protein-lowering trials, so they're watching our progress closely. In the case of Alzheimer's disease, of course, trials of amyloid-lowering drugs have proved disappointing, so our results provide a ray of light. We've shown that it is possible to go back to the source of the problem and prevent the production of these proteins, hopefully before they cause damage.

Do you think your announcement might also have tapped into the zeitgeist, in proving that experts are good for something after all?

Absolutely! At the end of the year people tend to take stock, and last December there was a feeling that 2017 had been a pretty challenging year for science and people who think that science is useful. This was a vote in favour of science, a palpable delivery on the promise of the genetic revolution.

Will it affect the uptake of the predictive test for HD?

After the Christmas break we got back to a very full inbox of referrals to our clinic. We always predicted that when we had a treatment that worked, lots of people

would come forward for testing, because the meaning of being at risk would have changed. It surprised us that many people interpreted *this* news as grounds for rethinking a previous decision not to get tested. It's not for me to say how they should decide as individuals, with regard to getting tested, but what I can say is, the bigger the tested population, the faster future trials will recruit and proceed.

Do you worry that people's expectations of the drug may be too high?

My view is that this is really good news and it should be celebrated as such. There is lots more work to do, and it will probably be at least five years before a drug is licensed, but it's like discovering your super deluxe Christmas present: the next day, you have to sit down and read the instructions, you might have to go out and buy batteries, but nobody can take that present away from you.

What is your ultimate goal?

> *"I want to help solve HD so that people no longer have to wake up worrying about it."*

If that happens before I retire, then I want a cure for male pattern baldness (see photo).

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Praça do Comércio, Lisbon

Photo: http://cyberfotografia.blogspot.de/2014/01/fotografias-de-portugal-praca-do.html

Dates for your diary

Save the dates for:

- RE(ACT) Congress, Bologna, Italy, 7-10 March 2018
- Orphan Drugs & Rare Diseases Global Congress, London, UK, 8-9 March 2018
- Brain Awareness Week—Outreach Event, Strasbourg, France, 15 March 2018
- European Conference on Rare Diseases and Orphan Products, Vienna, Austria, 10-12 May 2018
- Enroll-HD Congress (by invitation only), Quebec City, Canada, 20-22 May 2018
- MDS-EHDN Education Course: Chorea and Related Disorders, Poznań, Poland, 25-26 May 2018
- 4th Congress of the European Academy of Neurology, Lisbon, Portugal, 16-19 June
- 11th FENS Forum of Neuroscience, Berlin Germany, 7-11 July 2018
- EHDN2018 Plenary Meeting, Vienna, Austria, 14-16 September 2018